ALS ASSOCIATION
MESSENGER
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Save The Date – Walk-A-Thon

The Diamond Walk-Downtown on Saturday October 6, 2001, will benefit people with incurable Amyotrophic Lateral Sclerosis (Lou Gehrig's disease). Celebrate a life and honor those who have this fatal disease and those who have lost their lives to ALS by participating in this event. Begin at Exposition Park and take the first step toward a home run, with your family at your side. As you round first base and head for second, meet new friends and cheer them on. Cross second base, go for third, and enjoy fun times with everyone, all while walking to help those who need the most help. Hit third base and take your final strides toward home plate.

You've hit the homerun as you return to Exposition Park. Register today and hit a home run for patients everywhere, contact us at (818) 865-8067, fax (818) 865-8066, email ALSAGLAC@aol.com or online at www.ALSALA.org. Walk for a cure, a life or a memory. For more information contact the Greater Los Angeles Chapter of The ALS Association.

INSIDE THIS ISSUE

CHASING THE WIND—A SIMPLE WISHES EXPERIENCE

BY BARB PHILLIPS AND SILVIA CASTRO — Simple Wishes is a volunteer program that has been in place for 1 year now. To date, approximately 20 Wishes have been granted. Volunteers are matched with PALS (Persons with ALS) to 'help' them complete a simple task or activity. Examples of some Wishes include helping the PALS to write letters, sorting through and organizing recipes, organizing photographs, small chores around the home and organizing closets. Each Wish seems Simple in task, but in reality, relationships are building and developing that grow far deeper than ever imagined.

This story is to let the PALS know that they are contributing as much to the lives of the volunteers who help them as the volunteers are contributing to them. We have had far fewer Wish requests than we imagined and we feel that may partially be due to the PALS' feeling of not wanting to request assistance. This story reflects how the Simple Wish experience is one of true balance and symbiosis.

Silvia Castro had the kind of life many of us would barely endure. She and her family frequently moved between Costa Rica and the US. Changing cities nearly every year as a child, Silvia grew up with the values many young women aspire to. A nice home, a nice car, a husband and a family. The American Dream. From the adults in her life, she learned that if she worked hard and became a high achiever, she could have the things in life that would ultimately make her happy.


Silvia Castro

Silvia currently works at Rancho Los Amigos National Rehabilitation Center as a Certified Occupational Therapy Assistant. In the evenings, she was attending school working toward a Bachelor's degree in Business. When the Simple Wishes program started one year ago, she

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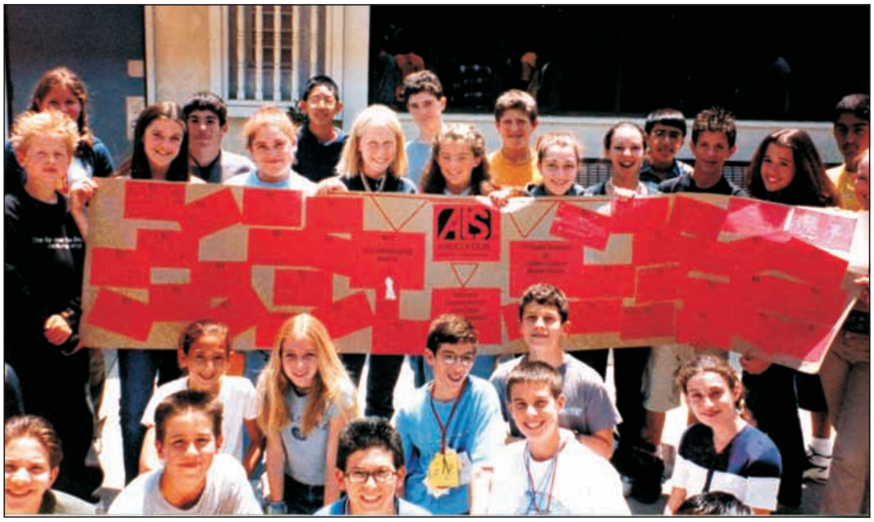
HONORING CONGRESSWOMAN CAPPS – OUR YOUNGEST ADVOCATES!


Debi Klein, ED

BY DEBI KLEIN, EXECUTIVE DIRECTOR — Recently Mrs. Brammer, a Social Science teacher at Lindero Canyon Middle School in Agoura Hills, California, invited me to speak to her 7th Grade students about working in a non profit agency. What an honor! I shared with the students the joys of working with a truly remarkable community, the ALS community, and the challenges that our Chapter faces every day.

Mrs. Brammer had spent several months encouraging her students to volunteer in their communities and many of the students had exciting experiences to share, as well. The afternoon was truly inspirational.

Imagine my surprise when Mrs. Brammer called to let me know that her students had been following the path of the ALS Bill (HR 353) and were delighted that the Medicare portion of the bill would be implemented shortly. These remarkable students had gathered together to write thank you letters to Mrs. Capps for her efforts in "passing the bill through Congress." The letters were assembled into a banner and presented to the Congresswoman during ALS Association National Advocacy Day. The following photos show the delight and joy that the students share with Congresswoman Capps.


Students at Lindero Canyon Middle School with poster for Congresswoamn Lois Capps.

Chapter representatives Dean Rasmussen, Dr. Jeannie Moller Fontana, Oscar Sepulveda and Dr. Linda Sepulveda, UCLA Football Coach Gary Bernardi, Brenda Bibee, and Chapter Staff Debi Klein, Molly Rockey, and Ann Verplanck, visited over twenty Congresspersons and Senators during Advocacy Day this past May. We discussed the difficulties that persons with ALS face. Our team focused on the need for increased funding for research, prescription drug benefits, home health town hall meetings and the production of an ALS postage stamp. The day was positive, productive and ended on a high note as Chapter delegates from across the country joined ALS supporters for special advocacy awards presentations.


L-R: Dr. Linda Sepulveda, Dean Rasmussen, Congresswoman Capps, Debi Klein, Molly Rockey, Jeannie Moller Fortuna, Gary Bernardi.

Simple Wishes, from page 1

was eager to volunteer her time. Her compassion stemmed from a long illness sustained by her mother when Silvia was a young girl.

As a Simple Wishes volunteer, Silvia was asked to contact Mrs. Patti Parillo. Diagnosed with ALS in July of 2000, Patti has rapidly been losing strength. Her father who lives in Florida was moving in with her and was sending his belongings in boxes for Patti to unpack. As Patti was preparing for his stay, she realized that she no longer had the strength or endurance she needed to move the hanging clothes out of the guest closet to make room for his things. She requested assistance through the Simple Wishes program.

In April, Silvia contacted Patti and they made arrangements to meet. When Silvia arrived at Patti's home, she was instantly in awe of the beautiful surroundings. Patti, an interior designer by trade, had a magnificent home with lovely things. But more than that, Patti was a beautiful woman. When she answered the door, Silvia was slightly taken aback by Patti's halo of blonde hair, her sparkling blue eyes and warm smile.

The moment was a bit awkward for both women. Patti invited Silvia in and informed her of what needed to be done. The initial moments were very business-like and a little uncomfortable. Silvia followed Patti into the guestroom where she had already started unpacking her father's clothing. Patti took a seat on the bed and started folding the clothes that she directed Silvia to place into the dresser drawers. This time was still formal and tense, so Silvia started asking Patti questions. Questions about her life, about her career, her family, and her illness.

Silvia learned that Patti lost her beloved husband just 2 months before she was diagnosed with ALS. This was very difficult for her. Silvia also learned that Patti worked very hard during her life. Every job she took on, she got promoted to the top position. She achieved her goals and was able to fill her life and home with beautiful things. But as Patti spoke, she had an amazing insight. She was beginning to realize that all those things meant nothing compared to her health and her relationships with her family and friends. Patti started to cry.

For the first time, Silvia intuitively knew exactly what to do as she got up from where she was sitting and went over to hug Patti. They held each other while Patti let go of feelings she hadn't been able to express earlier. Silvia held Patti for what seemed a long while and, not exactly knowing what to do, she started to talk. Silvia shared her story with Patti. The story about her life, about what it was like to move so often, what it was like to have a sickly mother and how difficult it was to be living in so many different places. Patti stopped crying and listened with all her heart to what Silvia had to say. Suddenly, she no longer was crying for her losses, but found the power within herself to be strong for someone else.

The women stopped working and talked for over an hour. They learned that they had similar goals and dreams, Silvia on one side of the mountain and Patti on the other. Silvia found that being in Patti's home, she was surrounded by all she aspired to be and to have in her life. As these two women from different worlds talked and shared, they both had the realization that life is so precious and too short. "We are always working so hard to surround ourselves with beautiful things, thinking that the things will bring happiness." Silvia said. "The reality is it is like chasing the wind. It is not the things in life that brings happiness, it is the relationships with family and friends, God, the people you love and your health."

Molly Rockey and Barb Phillips presenting the Greater LA Chapter's Volunteer and Simple Wishes porgram posters at the ALSA National Leadership Conference in Washington, D.C.

Silvia ended up working in Patti's home for over 3 hours that first day. They met a second time and went to church together. They are in contact with each other on a regular basis and they know that this is the beginning of a beautiful relationship.

Through this volunteer experience, Silvia realized that she was "chasing the wind" by pursuing a degree in business. Patti told her she was "an old soul" meaning that she has lived through so much more than other young people. In Silvia, Patti saw the grace and spirituality that Silvia herself had not seen. As a result of this relationship, Silvia has decided to change her career plans and is currently pursing a degree that comes from her heart, one where she can help people at another level.

During Patti's experience with her illness, she has come to learn that there are total strangers out there that are willing to help. She feels that anywhere she goes, another angel pops out to help her. Silvia's is Patti's angel.

"ASK THE EXPERTS" – A PALS'S PERSPECTIVE

BY GINGER ATAWAY WITH INSIGHT FROM CARL FROVA — Carl Frova is one of the most luminous people I will ever have the honor of meeting. When Molly Rockey asked if I would meet Carl to help him share his experience of ALSA's annual symposium "Ask The Experts", I said I would love to. A few moments later I felt slight trepidation try to nestle in. Although I do volunteer with the ALS Association, I had not spent time with anyone showing outward signs of ALS. One of the first things Carl said to me was, "my arms don't work at all. My legs work a little bit for now, I can sort of shuffle them. I use a wheelchair mostly." Meeting him has rocketed my acceptance, appreciation, and understanding, to an entirely new level. When I sat down to write, I thought, "there is no way I can make this only about the symposium." I felt I would be remiss to keep my experience of a such galvanized spirit living with this devastating disease to myself.

According to Carl, the most encouraging portion of the symposium was that on stem cell research.

Carl, now 64, was diagnosed with ALS in March of 1999. I tell him how great he looks and he says, he has lost fifty pounds; he used to do a lot of exercise such as tennis and skiing, to stay in shape. He said, "I find a lot of ALS patients were well conditioned physically." Carl's diagnosis came rather circuitously. While at a yearly check up, Carl mentioned he was having what is called fasciculation, or spasms on the surface of the skin, which the doctor suggested might be caused by myriad factors such as too much coffee, and or stress. The doctor told Carl to cut back on the coffee and if the twitching persisted to come back in a few months and he would send him to a neurologist.

Two months later Carl went back to his doctor and was guided to a neurologist who is the director of the MDA/ALS Research Center at USC. That day began Carl's many months of such testing as muscle biopsies, and spinal taps. He also spent two months on Vitamin B-12, because a B-12 deficiency can result in some of the same symptoms. He then spent some time with an Intravenous Immunoglobulin, or, IVIG. By this time about seven or eight months have passed since Carl's first doctor's appointment, and he was losing a lot of functioning in his right arm. "I know mine is slow, but not as slow as some." By March of 1999 the neurologist at USC said to Carl, "well, there is nothing more we can do for you." Carl asked pointblank, "Doc, do I have ALS?" To which the doctor responded, "Yeah, you have ALS. We'll call it non-standard, but yeah, you have ALS." Carl has said of the day he received the final result, "So this is how I got the diagnosis. You walk in and it says MDA/ALS Center, so you get a clue as to what is going on. I mean you go into this place for eight months and you know pretty well, unless they come up with something unique, that is what they are looking at."

Carl and his wife Barbara have attended three consecutive "Ask The Experts" and he claims "this one was the best by far; well beyond my expectations." According to Carl, the most encouraging portion of the symposium was that on stem cell research. In Carl's opinion, stem cell research is what offers the most hope. "That is where a lot of endeavors will be. I also think they will get a lot more than just ALS research; you'll get other neurological diseases looking into those areas which will be beneficial to the ALS patients. This is the only place you will find this, and I think they did an excellent job."

A handful of attendees felt the report given on nerve growth factors to be disappointing and unsettling, however, it is important to know that there has not been any progress in that area, which will lead to investigation in another arena rather than continuing a barren search. Carl was involved in one of the nerve growth clinical trials, so he found this portion to be of particular interest. "Being a scientist by nature, I think the negative is as good as the positive. At least you know areas not to explore."

As far as understanding the experts, and the technical jargon, Carl said, "they really brought it down to the audience level. Because of all the research Barbara has done, and we have read everything there is to read, we are somewhat aware of what is going on. So basically the presentations filled in the blanks, and then they brought stuff to the table that was new."

To illustrate the type of man Carl is, rather than cowering away in fear and depression following his diagnosis, he found the ALS Association's Greater Los Angeles office, walked in and asked what he could do to help. He and Barbara then attended their first "Ask The Experts", which led them to meet Dr. Graves from UCLA, thus subsequently inclining Carl to participate in a clinical trial. Presently he is down to 30% of his lung capacity, which means he has to use a BI-pap machine in order to sleep. Of his daily routine, Carl says, "basically I cannot even get out of bed in the morning, so Barb helps me. She has to bathe me, dress me,

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she brushes my teeth. We are lucky, we have adapted the bathroom to have the showerhead with the hose on it, and a small 3" lip on the shower, so it works for us. We have a two-story house, and we had a chair lift installed so we don't have to leave our home. You do little adaptations like that. So on the positive side we keep looking at what we have to do, changes we have to make so we can continue to live our life as normally as possible."

Carl goes on to tell me that nothing has modified in what they do as far as going out to dinner and being with friends. Every year since they have been married the two have gone to the Festival of Arts in Laguna Beach, and, he quickly adds, "we see no reason to stop. Still participating in life brings the most comfort and joy." For example, they decided to take a trip to Hawaii last February, "we put the wheelchair on the plane, and zipped over to Hawaii. We made sure the hotel had a roll in shower, because I cannot step over the tub anymore. The hotels are very accommodating, they really take care of handicapped people. There are accommodations -take advantage of them."

When the conversation turns toward advice he can offer anyone else living with ALS, he says "one thing it does is change the way you look at the world." He then says, "honestly, the best thing for ALS patients is to make sure you have a strong partner; I don't know what you tell them if they don't have that." Carl is careful to add, "the support people are going to need support people, and our kids have been great." He goes on to say, "I've just been very, very fortunate. I am not limited from doing anything, with Barbara." After a pause, he points to two beautiful drawings on the wall and tells me his wife is the artist. "Barbara is a fantastic artist, very talented pianist, incredible business person; very, very bright lady, and she didn't sign up for me to have a disease. Barbara and I are just soul mates. We found that out way back when, and it has only gotten better, not worse, and so I am just a very, very lucky guy."

In terms of additional advice, Carl says it is essential to "stay positive and enthusiastic. Take an active participation in whatever you can for whatever extent you can. Get involved right away, because you potentially only have a few years, so you better get involved early to get the benefits of whatever there is." Which leads us into discussion of one of the many things Carl is thankful for: the fact he can still communicate. He said, "just as we're talking today, and I have said to the people at the ALS Association, I have said to just about anyone who will listen to me, I will be happy to talk to anybody about anything if I can help other patients. If they are concerned about things, have them give me a call on the phone." Carl also suggested that people with ALS become tissue donors. "This is something every patient with ALS can do. That is how they are going to learn more about the disease and the cure." Several times during our conversation, Carl tells me that he always tends to see the brighter side of things. I mention how fortunate he is to have such a gift, that he has not thrown it away, to which he responded, "what do you get if you do that?" He also suggests that anyone with ALS read "Tuesdays With Morrie", because, he says, "it is not directly about ALS. It is about the things you have got to think about — about life."

The short time I was blessed to

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SHARING A BIT OF LIFE

BY JANET K. YAMANISHI, CASE MANAGER — After reading one too many Martha Stewart magazines and frequently viewing the Home and Garden channel, I became inspired to give gardening a try. After all, they made it seem so easy. Yes, I have tried many times in the past and failed miserably. The flowers withered and the weeds flourished. Yet, somehow I knew this time would be different.

I have a daily reminder of the dynamic couple that face each day finding joy and creating beauty with simple plants in an everyday garden.

I did not know as I set out for a home visit, that my renewed interest in gardening would be a shared interest between my clients and myself. As we sat and talked, I marveled at this couple, living everyday with ALS and living everyday with an appreciation for life and each other. At the conclusion of our visit, as they walked me out of their home, I stopped for a few minutes to admire their garden. As we chatted they told me how their garden developed, borrowing ideas from garden tours and local nurseries. Together they have created a unique and lovely corner for their world.

I shared with them my past feeble attempts and my endeavor to try again. Then the unthinkable happened — they gave me cuttings for my beginning garden. Assuring me if I "just stick 'em in the ground," they will grow. Now when I walk out my back door and see the cuttings beginning to take hold, I am encouraged, I can do this! I came away that day with more than starts for my garden. I have a daily reminder of the dynamic couple that face each day finding joy and creating beauty with simple plants in an everyday garden.

OUR GROWING CIRCLE OF FRIENDS

BY MOLLY ROCKEY, DIRECTOR OF VOLUNTEER SERVICES — My husband, Ed, was invited to speak at an international business symposium in southern Sweden in June. While making our travel plans I got a brainstorm! I would have some extra time to wander about while he was speaking, so I checked the world-wide-web for ALS/MDA chapters in Scandinavia and found "Muskelsvindfonden" at the Institute for Neuromuscular Disease just north of Copenhagen, Denmark. I e-mailed their Director, Marianne Frederisksen, and asked if we could arrange a meeting while I was in her part of the world. She warmly responded and arranged a time for us to meet.

The day of our appointment I left Lund, Sweden by train to Malmo, changing cars there to travel on to Hellerup, Denmark. It was an exciting experience to figure the schedules and how to purchase the tickets with two different currencies. Two hours later I was at the doorstep to the Institute, five minutes before the appointed time. Everything was working perfectly.

I found my way to the conference room that Marianne had reserved and was delighted to find thermoses of strong, hot European coffee, and delicious Danish (yes, buttery and flaky, stuffed with apples and peaches). Marianne had arranged for several people to meet me. PALS Henning Dahl was there to help me understand the Danish health care system. Occupational Therapist Lisa Holter and Susanne Jakobsen, RN, were there to share programs and to learn about Simple Wishes.


Visiting the Institute for Neuromuscular Diseases in Copenhagen, Denmark: Molly Rockey, Susanne Jakobsen, RN, Marianne Frederiksen, Managing Director of Institute, PALS Henning Dahl and Lise Holter, OT.

The two hours we spent together just flew by. We discovered differences in the scope of our Support Group meetings and shared ideas on how we might incorporate new ideas so that more people could benefit. When explaining about the Simple Wishes program Henning shared that while the Danish government is so great at arranging nursing care, hospitalizations and the use of medical equipment, there is no program to help PALS write love letters, complete family scrap books, help with flower gardens and telephone calls. It was a positive and emotional exchange as the vision of "Simple Wishes Denmark" began to form.

The five of us talked about fundraisers (they are very interested in our golf tournament and upcoming Walk-A-Thon and shared the excitement of their summer concert series with me) and handicapped accessible vacation spots. We decided we wanted to leave the meeting with one piece of shared work that symbolized our time spent together. We came up with what we think is a wonderful idea. What if we start a pen-pal e-mail for the children of PALS by connecting children of the same age in California with new friends in Denmark? The requests will come through the Volunteer Services department. This way our children can share their hopes, fears and experiences with their peers. To expand the concept we will add a "Children's Page" to our web-site and have children send in questions that other children can answer about what helps them most when living with a relative with ALS. To have your children participate, please call me at the office at (818) 865-8067.

And if anyone is wishing to travel to Denmark, I have the information to share about a completely wheelchair accessible resort designed for families with beach, kitchen, bathrooms and recreation facilities created for people with neuromuscular diseases. If you want to visit the "Musholm Bugt Feriecenter" web site, sign on at www.musholm.dk

And also, as always, thank you to all the volunteers who have stepped up to help at Ask the Experts, processing the many mailing these past months and helping to plan the "Find Your Authentic Swing" golf tournament and "Tip Your Hat to Friends and Fashion" afternoon tea and fashion show. Your efforts make things happen!

TEN REASONS TO CONTACT ME

BY FERNE HAYES, PATIENT LIAISON/EQUIPMENT LOAN POOL — Greetings! Many of you know me as director of the chapter's Equipment Loan Program, a source for a variety of used medical equipment. Did you know you might also contact me for the following?

✦To get information about the use of feeding tubes for people with ALS.

✦To borrow a video that presents both sides of the home ventilator issue, showing a person who has been using a ventilator at home for 17 years and another who has decided not to use a ventilator, in case of respiratory failure.

✦To find resources for buying, renting or selling wheelchair accessible vans.

✦To discuss ways to make your home accessible for your changing needs.

✦To tell me which disposable medical supplies you are paying for out of pocket and to be put on a list to be notified if any of those items are donated.

✦To receive a copy of the Equipment Loan Pool's "Small Items List" – several donated items that assist with feeding, dressing, etc. are available for free.

✦To get a list of available printed material on various issues faced by people with ALS.

✦To request samples of communication boards useful for people who can indicate "yes" with some consistent movement.

✦To discuss ideas for meeting your caregiving needs – involving family/friends, hiring from an agency, hiring privately.

✦To request a case manager referral when you need in-depth assistance in organizing your resources to meet the demands of the disease.

And of course,

✦To borrow or to donate used medical equipment in good condition.

As Patient Liaison, I collect a variety of information and resources useful for managing the symptoms of ALS. Contact me and let's talk! (626) 449-0605; elpferne@aol.com

CAREGIVING AND LOSS

BY LOTHAR DELGADO, MA, ALSA CASE MANAGER — "Large sorrows hit us out in the open and we are well aware of the effect on our lives. Small sorrows creep in unaware and silently collect in the bottom of our soul." This quote of D. Manning from his book, Share My Lonesome Valley: The Slow Grief of Long Term Care, was a fitting conclusion to the Hospice Foundation of America's recent teleconference on Care giving and Loss. Cokie Roberts moderated this year's teleconference, as she has for seven previous yearly events. Roslyn Carter was the featured speaker and she highlighted the crisis in care giving in America today. We survive serious accidents and illnesses, live longer and encounter problems in aging. For family caregivers and professional caregivers the task at hand can alternate between being a rewarding mission or a lonely, stressful and overwhelming one.

Almost all family caregivers, but especially those providing the most intense levels of care, report significant physical, emotional and financial stress. Many must give up employment to care for a loved one with a chronic disease such as ALS. Others must work through the loved one's illness, paying for care that they would prefer to give, in order to sustain employment and benefits.

A certainty of care giving is that it involves loss. Perhaps the most important is that of the person one is caring for and some of the ways they enjoyed life together before the illness. There are also losses of time, independence, friends and control as caregivers become absorbed in their role. We can always rationalize our losses through feelings of guilt for thinking about ourselves when our loved ones seem to be losing so much more. Perhaps the greatest gift we can give as caregivers is to be "brave companions on the road" of life.

Caregivers need support. The ALS Association of Greater Los Angeles provides case management services to people with ALS and their caregivers through a caring and empathetic presence, connecting caregivers to concrete services and community resources, and vigorous advocacy. We believe that caregivers have rights, too. These rights include: the right to rest, the right to honesty, the right not to be second-guessed about medical decisions, the right to family sensitivity about time and expense, and the right to receive gratitude. Please contact the ALS Association to find out more about our case management services.

CALLING ALL VETERANS

BY ANN VER PLANCK, MA, PATIENT SERVICES DIRECTOR — In May, I had the opportunity to attend the National ALS Conference in Washington, DC. One of the best speakers, in my opinion, was a nurse who was also a Veteran. She gave us a step-by-step method for how to sign up for VA benefits. She even gave us her email address so we could write to her if things didn't work out the way she outlined for us. In this article, I want to tell you what she told us and I hope it will encourage all of you PALS who are Veterans to consider going to your local VA and signing up for the benefits you are apparently entitled to.

Here is what she shared with us:

1. Anyone can receive Veterans benefits after serving for 180 days in the Armed Forces.
2. Only people with dishonorable discharges are not eligible for VA benefits.
3. You can receive VA benefits even if you have a non-service connected disorder.
4. It should only take 1.5 hours to sign up and you can become eligible immediately for VA benefits.
5. There is no income requirement.
6. ALS qualifies as a Category 7 under the VA health care priority categories. She states that it can also be classified as Category 4 and 5—a catastrophic fatal disease, or spinal disease.

It is possible that you will qualify for the following: speech evaluations; AAC devices; in home accommodations such as a lift on the car or a portable ramp; two wheelchairs (one power and one manual) hospital beds with control panels and in home care. She states that a Veteran can get Rilutek for $2/month. You might have to pay a $50 co-pay to see the doctor, but then the Rilutek is only $2/month. For people who have no other insurance to cover Rilutek, the $50 co-pay might be worth it.

How to sign up: You need to find those discharge papers and make copies of them. Not having your discharge papers is apparently what slows down the process of signing up for VA benefits. Take a copy of the discharge papers, a copy of your medical records, and go to your local VA. According to the VA nurse, you just have to show your discharge papers, medical records, they put you in the computer and you're eligible for benefits.

Now, being the skeptic that I am, I'm not sure whether this will work or not. But it seems worth a try. This woman was quite adamant that it will work and has offered to help us if you have problems. If you are currently working with one of our Case Managers, ask them to help you with the process. I will make the information I learned available to them, including the name and email address of the woman who gave me this information. If you are not currently assigned to a Case Manager and would like some assistance, call Ferne Hayes at (626) 449-0605 to get assigned to one.

ALSA — LA CHAPTER SUPPORT GROUPS

Pasadena Support Group

Lamanda Park Library;
140 South Altadena Dr., Pasadena; Third Saturday of each month at 2:00 p.m.

Contact John Jones, MFCC at (626) 524-7081, for more information.

Ventura Support Group

City of Westlake Village Community Room, located at Westlake Village City Hall and Library, 4373 Park Terrace Drive, Westlake Village, Fourth Saturday of each month, 1:00–2:30 p.m.

Contact: Joyce Lauterback (818) 542-7048 for more information

Monolingual (Spanish) Support Group

Note: New Location
City Terrace Library, 4025 East City Terrace Drive, Los Angeles, CA 90063; Third Saturday of each month from 3:00–4:30 p.m.

Contact: Martha Mowatt at (562) 889-9452 for more information.

Westside

American Red Cross Building, VA Grounds, 11355 Ohio Avenue, Los Angeles, CA 90025, Meeting Room 7; 1st Saturday of the Month!

For Information, Contact Support Group Leader John Jones, MFCC (626) 524-7081

REFLECTIONS

BY JOHN JONES, MFCC, SUPPORT GROUP LEADER — In one support group, I noticed that EVERY ONE of the significant others' introduced the person with ALS as "the patient" (with some persons with ALS, they could speak themselves, yet the significant other still introduced them). I asked the group members who were Persons with ALS what it was like to be referred to as "the patient"? They all responded with "ok, fine, no problem..." This greatly surprised me. I wondered why I was surprised and why these people with ALS didn't respond differently? In my wonderings, I looked up the word "patient" in a huge dictionary. Here are some of those definitions:

1. a person who is under medical treatment.
2. a person or thing that undergoes some action.
   ab. a sufferer or victim.
4. bearing provocation, annoyance, misfortune, delay, or hardship without complaint, anger, or the like.

Well, I thought, this explained perhaps some of the reasons why persons with ALS might be ok with being referred to as "the patient." It was how we were taught. This made sense, but then I started wondering why I didn't feel quite ok with this. Here's what I came up with: If I were a person with ALS, I'd probably feel like I was being perceived as only "the patient," and that all of me was not being considered. Among the persons with ALS that I know, most still enjoy those things that they did prior to being diagnosed, like music, the movies, reading, dining out, visiting friends, family and loved ones, etc... Most people with ALS that I know have the same personality, likes, dislikes, needs, desires, and wishes that they did prior to being diagnosed (if not more so following the diagnosis!). So, I think I might feel like I was being reduced or pigeonholed or relegated to only one role. I also had several strong reactions to the definitions that were listed, especially the fourth one! It states that a patient is a person that "bear(s) provocation, delay, hardship without complaint, anger, or the like," my thought was: ARE THEY CRAZY? Well, it seems like the term "patient" if used as a verb refers to a virtue. I began to wonder why our feelings aren't a virtue too, specifically "anger, and the like"? Well, what I came up with was that unfortunately, this is also how we were also taught. How very sad!

I welcome ALL of your thoughts, feelings, and feedback at our next emotional process support group.

THE NECESSITY OF EVALUATIONS

BY LINDA MADOLE, DIRECTOR OF AUGMENTATIVE COMMUNICATIONS — Greetings. Over the past couple of months, I have encountered at least three or four PALS in need of augmentative/alternative communication, whom either did not know that our loan pool existed or figured that AAC was not an option to them. I realized just how important it is to impart as much information as possible on how to access our loan pool, and/or get the necessary evaluation(s) for augmentative/alternative communication. As I pass this information on to you, I am inspired by the motto, "Where there's a will, there's a way." If a person has even just a blink of an eye, there may be communication!

The ALSA/GLAC Loan Pool serves to loan augmentative/alternative communication equipment, free of charge, to persons diagnosed with ALS who are in need of communicative assistance. The type of equipment to be loaned is based on each person's individual needs as identified through a complete assessment, which is conducted by a certified speech-language pathologist (not affiliated with the ALSA).

I. Criteria for Accessing Loan Pool

The eligibility criteria for accessing the loan pool are as follows:

- ✦ ALS Diagnosis and
- ✦ Living in the Los Angeles, Ventura, or San Bernardino County and
- ✦ Possess renters/homeowners insurance by which the loaned equipment will be covered and
- ✦ Do not possess health insurance to cover the purchase of a device or
- ✦ Has been denied authorization for augmentative communication equipment from his/her health insurance and cannot afford to purchase own AAC equipment or
- ✦ Equipment may also be loaned on an interim basis while waiting for health insurance (i.e. Medi-Cal, Medicare) to purchase equipment. Upon receipt of the equipment purchased by health insurance, the borrowed equipment would be returned to loan pool.

II. Procedures for Accessing Augmentative Communication Loan Pool Services

- ✦ PALS or responsible party contacts the Augmentative Communication Loan Pool Director, via telephone or e-mail.

Please see Evaluations on page 11

FEELINGS… NOTHING MORE THAN FEELINGS…

BY JOYCE LAUTERBACK, VENTURA COUNTY SUPPORT GROUP LEADER — PALS encounter numerous problems coping with the progression of this disease. Problems with breathing, mobility, speech or swallowing become obvious and can be addressed by many of our staff or adjunctive support services. After an assessment of the problem, a reasonable solution can be found in the form of treatment, equipment or a different way of doing things.

Most people in general have difficulty identifying what emotions they feel. People have even more difficulty expressing them out loud to someone else, especially a loved one.

But what do our PALS and CALS do when the problems are emotional? Most people in general have difficulty identifying what emotions they feel. People have even more difficulty expressing them out loud to someone else, especially a loved one.

As a therapist in private practice, my primary goal of couples therapy is not to find a solution to the problem presented but to assist the couple in learning how to communicate about the problem presented. When she/he lets the other person in on what she/he is thinking, feeling and wanting, the solution often presents itself. It is difficult to be honest. There are many underlying, sometimes unconscious concerns…

"If I say what I'm feeling, if I let her/him know this bothers me…"

"He'll pull away."

"I'll hurt her feelings."

"He'll think I'm demanding."

"She'll get angry."

"I just want to keep the peace."

"I must be the strong one, because this is so hard on him/her."

The patterns of how we interact with each other are established when we are young. We learn how to express ourselves or not express ourselves from the family we grew up in. Often, the adult relationships we enter into, match the patterns we are familiar with. Patterns of interacting do not change overnight.

In my 20 years experience as a home health physical therapist, I find that illness, aging and dying usually amplify the already existing patterns and personalities. With ALS, some people will be the perfect patient. They will not complain and will never make demands of you. They'll be cheerful and bright and help make you feel better about dealing with their ALS. Others will be calling the shots from their wheelchair or hospital bed. They'll tell you exactly how to transfer them and you better not deviate from the sequence or they will get angry at you for not "doing it right." They don't want anyone feeling sorry for them.

What you will never know from some people is how frightened they are, how angry or how sad they are. You will never know how helpless they feel. You'll never know what their secret wishes are.

It's difficult for people to communicate in a healthy, honest way. Not only are we influenced by family patterns but also culture, abuse, divorce, alcoholism, family rules and many other things, play a role in how we relate and interact with each other. Then add to the mix, ALS. There is often a sense of guilt about being honest, a sense of protecting the other by not being honest. Sometimes all these feeling are shoved down inside.

The good news is that all of these patterns are learned behaviors, so… we can unlearn them. With a little coaching and education in communication tools, we can learn new patterns of behavior. We can learn to become aware of and verbalize what is going on inside of ourselves. The surprise is that people usually feel closer to each other after talking from their hearts.

In the next newsletter, I will cover specific tools to use for effective communication. In the meanwhile…begin to pay closer attention to what you are feeling. Notice if you express it verbally or in actions. If you become aware that you are not expressing yourself as honestly as you would like to, start to think about the reasons why you may not be comfortable doing so.

Evaluations, from page 9

✦ The AAC Director will respond to the inquiries within 24 hours. Upon discussing the process for qualifying for participation in the AAC program, both the AAC Director and the PALS/or family member contact the appropriate agency to schedule a speech evaluation, if not already conducted, to determine appropriate device. Both the SLP and the AAC Director verify insurance coverage possibilities.

✦ Once the speech evaluation is completed, a written report is submitted to the AAC Director, with specific recommendations for appropriate equipment for the PALS. Upon review of this report, and communication with the SLP, a determination is made regarding the needs of the PALS.

✦ The AAC Director reviews the loan pool inventory list to determine if the recommended device is available. If the device is available, the AAC Director schedules a time to meet with the PALS and family members to deliver the device, or schedule training with a designated trainer for that particular device. If the device needed is unavailable, the AAC Director reviews the budget and determines if the device meets the established criteria for purchasing new equipment. If the budget permits, a copy of the speech evaluation, along with the written recommendation of the AAC Director is submitted to the Director of Patient Services for approval.

✦ The Director of Patient Services reviews the reports and determines if the request is valid. If denied, the Director of Patient Services will offer alternative solutions.

✦ Once the equipment has been ordered and delivered, the AAC Director coordinates the delivery of the equipment as well as the signing of the appropriate loan agreement and other pertinent documentation. The AAC Director then arranges a date for training on the equipment for the PALS and his/her caregiver(s).

The following is a list of assistive technology centers, which provide augmentative/alternative communication evaluations by trained therapists. If you are interested in acquiring more information regarding AAC evaluations, please refer to the location nearest you or call the ALSA/GLAC AAC loan pool director at 310-514-8228.

✦ Las Floristas Center for Applied Rehabilitation Technology (CART), in Downey, CA. Phone: 562-401-6800 (Martha).

✦ Casa Colina, in Pomona, CA. Phone: 909-596-7733 – ext.3041 (Heather).

✦ Assistive Technology Center @ Goodwill Industries, in Los Angeles, CA. Phone: 323-223-1211 – ext. 2357 (Marta).

✦ Assistive Technology Exchange Center, in Santa Ana, CA. Phone: 714-836-0640 – ext. 455 (Ramon).

MESSENGER

The ALS Messenger is published four times annually by the ALS Association, Greater Los Angeles Chapter. The ALS Association is the only non-profit, national voluntary health organization dedicated solely to the fight against Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) through research, patient support, information dissemination and public awareness.

P.O. Box 565
Agoura Hills, Ca. 91376-0565
(818) 865-8067
fax (818) 865-8066

Ask the Experts, from page 5

spend with Carl is one of the brightest mornings I will ever have. Carl Frova has certainly changed the way I look at the world. Through the words of a magnificent man living with a wretched disease, I can tell you, "I am just very, very fortunate."

CART'S CORNER...

Exploring Your Computer Options

BY BOBBI JEAN TANBERG, COTA — Are you a computer user? Are you starting to have some difficulty using the keyboard and mouse? Before spending your money on fancy or expensive alternative computer access technology, start by exploring the options you already have on your computer.

Accessibility Options are FREE and located in the Control Panel of your Windows operating system. Click on the Start button, go to Settings, go to Control Panel. Click on the Accessibility Options icon, the graphic is the universal handicap symbol, you can't miss it. Here you will find adjustments for your keyboard, your display and ways to move your mouse.

Keyboard Options

StickyKeys will allow you to activate the Shift, Control, and Alt key by pressing one key at a time. For example, normally you have to simultaneously hold down the Shift key and the letter you want to capitalize. When StickyKeys is turned on, you can touch the Shift key, then letter you want capitalized in sequence. The next letter automatically returns to lower case. This is particularly useful for people typing with only one hand or those using a pointer.

FilterKeys will ignore brief or repeated keystrokes, or slow the rate in which a letter will repeat. This is helpful for people who have a tendency to push down a letter key too long or accidentally hit letters while moving from one key to another. There is a range of adjustability for this option.

Another option for reducing accidental hits on the keyboard is to purchase a keyguard. A keyguard is a plastic shield that sits over the keyboard and has a hole for each key. You may rest your hand on the keyguard while moving toward the desired letter without accidentally activating the other keys. You may need to send your keyboard in, or just provide them with the necessary information.

An inexpensive solution for those having difficulty seeing the small letters on a standard keyboard is the use of vinyl adhesive letters. Vinyl adhesive letters are available in a variety of sizes, and can be purchased at a local discount or stationery store for about $3.

Mouse Options

MouseKeys allows you to control the mouse pointer with the number keypad on your keyboard. When this feature is turned on, the pointer will move in the same direction as the number, relative to the keyboard. The number 8 will move the cursor straight up, 2 will move it straight down, etc. Selecting corner numbers will move the pointer in diagonal directions. Number 5 is the left click button and 0 allows you to click and lock. This function is needed to move and resize windows or drag as when playing solitaire.

Another FREE alternative to using the mouse, is to use "keyboard shortcuts". Many of the activities that we do with the mouse, can be done by using a control key combined with a specific letter. The ALT button, along with the underlined letter of the item in the toolbar, will open that specific file. Once the file is open, type the underlined letter for the function that you desire. For example, when using your mouse, you move the pointer to File and click, then drag down and click on Save. Through keyboard shortcuts, you can type ALT "F", the File menu will drop down. You can then either use the arrow key to move down to Save, or type the letter underlined, i.e. "S" to save.

Some individuals have greater success using a Track Ball instead of the mouse. The Trackball requires less arm movement and coordination than the mouse. The Kensington Expert Mouse 5.0 is a nice solution because the ball is large and the buttons can be programmed to perform any function; click, double click, drag or right click.

Display Options:

While in the Accessibility Options file, go to Display. In this menu you can change the color contrast and font size on your display. This will affect your Window Menus and Tool Bar, but not the document that you are working on in your word processor. Changes in font sizes can be made through the font or format menu tool bar in your word processor.

Resources:

Kensington Expert Mouse 5.0
Global Computer Supplies
2318 East Del Amo Blvd.
Dept 73
Compton, CA 90220
(800) 845-6225
Item #: 94706
Cost: $99

Keyboard Keyguard

Turning Point, Therapy & Technology, Inc.
P.O. Box 310751
New Braunfels, TX, 78131-0751
(830) 608-9812.
www.turningpointtechnology.com.
Cost: ranges from $65-$150.

Custom made for any laptop or desktop computer keyboard, AAC device, Intellikeys keyboard, talking books and game boards. You may send a good photocopy of the keyboard, if the image is distorted, you may need to mail in the keyboard. Time required is

Please see CART on page 15

DONATIONS, MEMBERSHIPS AND MEMORIALS

The Greater Los Angeles Chapter of the ALS Association is truly grateful for the support we receive. The following acknowledgment lists persons and groups who contributed to our organization during the period of April, 2001 through June, 2001. Through this donation and support program the Chapter provides a way to remember and pay tribute to those who struggled valiantly in battling ALS. In addition, because of your caring and support, we are able to continue providing valuable patient services to individuals with ALS and their families, and to support needed research.

If a family member or friend has died of ALS and you wish to honor their memory, you may, in lieu of flowers, request donations to the Chapter. Please designate in the death notice that donations should be made to The ALS Association, Greater Los Angeles Chapter, P.O. Box 565, Agoura Hills, CA 91376-0565. You may also request a supply of tribute envelopes to have on hand at the funeral home by calling (818) 865-8067.

Individual Donations $1-$500

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Clarabel Scott
Lois Stephens
Kathleen Wood

Charlotte Zelon
Seymour and Estelle Markowitz

ANTICIPATED DIRECTIVES—FROM THE STATE OF CALIFORNIA

BY PEDRO LOZA, CASE MANAGER — It is very important for PALS and their families to address certain legal and financial issues as early in the disease process as possible. If not properly addressed, PALS and their families can suffer financial ruin and emotional devastation.

Legal issues must be dealt with quickly while the PALS is still in good health. If you have assets of value you need to have an attorney who specializes in Elder Care or Disability Care. Depending on your financial situation, you may find you have to have several documents drawn up to preserve the financial health of you and your family. Advance medical directives include Living Will, Health Care Proxy, and Durable Power of Attorney. These refer to your treatment preferences and can designate another person to make decisions on your behalf should you become incapacitated.

Last Will and Testament

Everyone needs a will but this is something most of us put off until we are older. PALS cannot afford to wait, so it's recommended that you get your will done and out of the way fairly soon after diagnosis.

Insurance Beneficiaries

Look at your life insurance policies and ensure that the proper beneficiaries are named and that all premiums are paid up to date. Send a letter to your life insurance company asking them to verify your coverage just to be on the safe side.

Names on Deeds and Titles

Depending on your financial situation, you may have a house, vehicles, land, or businesses in your name. You may want to consult with your attorney to see if the names on deeds and titles should be changed. If you are going to be applying for a Medicaid Waiver program, you should note that there are limits to the amount of assets you can have in your name in order to receive benefits. Some PALS find it beneficial to have their names removed from house deeds and vehicle titles so there is no chance they could be attached by future creditors.

Living Will

A Living Will is a written document that specifies what type of medical treatment you desire in case you become incapacitated. The Living Will can be general or specific and usually includes a statement about whether artificial life support should be used to maintain an individual's life. The Living Will can be modified or changed at any time depending on the PALS's wishes. A PALS may decide he wants no artificial life support, and if it is written in his Living Will, his wishes will be honored even if he is unconscious and cannot speak for himself. A PALS may decide he wants to be kept alive through the use of a ventilator but may not want to be kept alive if he was in a serious accident and suffered brain loss. The Living Will can be drawn up to accommodate the PALS's wishes.

Health Care Proxy

Also called the Health Care Power of Attorney, the Health Care Proxy is a legal document in which a PALS designates another individual to make health care decisions if he or she is incapable of making their wishes known. The Health Care Proxy has the same rights to accept or refuse treatment that the PALS would have if he or she were capable of communicating such decisions.

Durable Power of Attorney

The Durable Power of Attorney is a legal document that allows another individual to execute legal documents on a PALS's behalf. This means that a designated person can sign checks, pay bills, make bank transactions, etc. for the incapacitated PALS.

DIRECTIVAS ANTICIPADAS

PEDRO LOZA, MANEJADOR DE CASOS — Es muy importante que PALS (Persona con ALS) y sus familiares hagan certas cuestiones legales y financieras tan pronto como sea posible durante el proceso de la enfermedad. Si no està hecho correctamente, el PALS y sus familiares pueden sufrir de problemas y perdidas financieras asi como devastaci"n emocional.

Las cuestiones legales deben ser tratadas rapidamente mientras que el PALS todavia esta en buena salud. Si usted tiene cosas de valor, se recomienda obtener los servicios de un buen abogado. Usted necesita tener un abogado que se especialice en cuidado de personas de la tercera edad o cuidado de inhabilidad. Dependiendo de su situaci"n financiera, usted debe saber que tiene que elaborar varios documentos para preservar la buena situacion financiera de usted y de su familia. Las directivas mèdicas anticipadas incluyen testamentos en vida, poder del cuidado medico y poder durable legal. Estos se refieren a sus preferencias del tratamiento y puede asignar a otra persona para tomar decisiones en su nombre en caso de que usted se incapacite.

La Ultima Voluntad y el Testamento

Todos necesitamos hacer un

Please see Directivas on page 15

RELAY SERVICE

BY MARTHA MOWATT, MONOLINGUAL SUPPORT GROUP LEADER — Did you know that the State of California has a telephone “relay service”? The California Relay Service (CRS) allows individuals with a TTY (telecommunication device with keyboard and visual display) to communicate with others without a TTY and vice versa. As the word “relay” indicates, a trained operator is on the line relaying the conversation as it is occurring between the callers. The operator reads the text from the TTY caller and speaks it to the other caller. Likewise, the caller without the TTY speaks to the operator who then types it for the TTY caller to read. This service is also available for international calls.

You must be wondering about the cost of this service. The cost for CRS is free! All California telephone service consumers are billed a small surcharge on their monthly telephone bill. The surcharge finances this and other services for individuals with limitations.

To find out more about California Relay Service you can contact a customer service representative at:

MCI/CRS: 800-735-0373 (voice)
MCI/CRS: 800-735-0370 (TTY)
Sprint/CRS: 800-676-3777 (voice/TTY/ASCII)

For those with difficulty being understood Speech to Speech Relay provides operators to speak on their behalf: 800-854-7784

Directivas, de pagina 15

testamento, pero èsto es algo que la mayoria de nosotros dejamos hasta que somos màs viejos. PALS no puede permitirse esperar, asi que se recomienda que lo haga lo mas pronto posible despuès del diagnostico.

Beneficiarios del Seguro

Revise la poliza y clausulas de su seguro de vida y asegurese de que nombren a los beneficiarios apropiados y que todos los pagos sean hechos en el tiempo especificado.

Los nombres en las acciones, escrituras y titulos.

Dependiendo de su situaci”n financiera, usted puede tener una casa, vehiculos, propiedades o negosos a su nombre. Usted puede consultar con su abogado para ver si los nombres en las acciones, escrituras y titulos deben ser cambiados. Si usted va a solicitar un programa de Medical, debe saber que hay limites en la cantidad de bienes que usted pueda tener a su nombre para poder recibir los beneficios de este programa. Algunos PALS encuentran beneficiable quitar sus nombre de las escrituras de la casa y titulos del vehiculo y asi no tener ningun riesgo y evitar problemas con futuros acreedores.

El Testamento en Vida

Es un documento escrito què especifica que tipo de tratamiento mèdico usted desea en caso de que usted se incapacite. El testamento en vida puede ser general o especifico e incluye generalmente una declaracion acerca de la ayuda de vida artificial y si debe ser utilizada para mantener la vida de un individuo. El testamento en vida puede ser modificado o cambiado en cualquier momento dependiendo los deseos de PALS. Un PALS puede decidir su no desea ninguna ayuda de vida artificial, y si se escribe en su testamento en vida, sus deseos seran realizados incluso si el esta inconsciente o no puede hable por el mismo. Un PALS puede decidir si desea ser mantenido con el uso de un ventilador y tambien puede no desear ser mantenido con vida si el estuvo en un accidente serio y sufrio de muerte cerebral. El testamento en vida puede ser elaborado y acomodado a los deseos del PALS.

El poder del cuidado medico

Tambièn llamado poder mèdico legal, el poder del cuidado mèdico es un documento juridico en el cual un PALS senala a otro individuo para tomar decisiones del cuidado mèdico si el o ella es incapaz de hacer saber sus deseos. El poder del cuidado mèdico tiene los mismos derechos de aceptar o rechazar el tratamiento que el PALS tendria si el o ella fuera capaz de comunicar tales decisiones.

El poder durable legal

Este es un documento juridico que permite que otro individuo ejecute documentos legales a favor del PALS. Esto significa que una persona asignada puede firmar cheques, pagar cuentas, hacer transacciones bancarias, etc., para el PALS incapacitado.

CART, from page 12

approximately 2 weeks.

Also you may want to check: www.microsoft.com — go to “Accessibility”.

Bobbi Jean Tanberg is a Certified Occupational Therapy Assistant working at the Center for Applied Rehabilitation Technology, CART at Rancho Los Amigos National Rehabilitation Center in Downey. For more information on alternative computer access methods, contact CART at (562) 401-6800.

WE ARE A COMMUNITY

BY CECILE FALK BALSER, PHD, CHAPTER PRESIDENT — It is kindergarten, and my teacher is teaching the class a song with this verse, "I know my name and address and telephone number too."

It is the end of the day of "Ask The Experts," May, 2001. I am commenting to Dr. Michael Graves that I am delighted that everyone seems to have enjoyed this very technical meeting given by the scientists from around the country. He comments to me that not only was information imparted, but those attending our program now have a sense of all the people out there who are working for a cure and treatment for ALS, and knowing this is important.

When the diagnosis of amyotrophic lateral sclerosis is made for us, or someone in our family, it can be a very lonely and isolating experience.

Before you deem me daft let me explain my association between these two events. Clearly our understanding and sense of community changes developmentally with time and with situation. During childhood, it is of utmost importance that we know how to find our family should we be separated from them. Until we are introduced to the mailman or our first teacher, family is our main sense of community.

When the diagnosis of amyotrophic lateral sclerosis is made for us, or someone in our family, it can be a very lonely and isolating experience. We in fact do feel lost. The doctor has given us the name of this strange illness, which is going to change our lives.

To whom can we go for help? Who understands? Now you are being introduced to the ALS Community. Some of us deal better with new neighbors than others. But it is very important for everyone to know the resources available in their community. The ALS Community has much to offer PALS and family. There are many scientists, professionals and volunteers out there ready to fight and assist you. We can help you connect to the vast network of people who will understand and be able to be of assistance with issues of day-to-day living, insurance navigation, and ongoing research. Knowing this will make you feel less alone and lost. So please, as the youngster's song suggests, remember our name and address and telephone number too (they didn't have e-mail when this song was written). The Greater Los Angeles Chapter of The ALS Association, P.O.Box 565, Agoura Hills, CA 91376, 818-865-8067.

SERVICIO DE RETRANSMICIÓN

BY MARTHA MOWATT, MONOLINGUAL SUPPORT GROUP LEADER — Sabia usted que el estado de California ofrece un servicio llamado California Relay Service (CRS) (Servicio de Retransmición de California). El servicio de retransmición permite la comunicación telefonica entre una persona con un dispositivo TTY (equipo de telecomunicación con teclado y pantalla) y con alguien con teléfono regular y vice-versa. El programa hace uso de un/a operador/a capacitada para transmitir la comunicación. El individuo con el dispositivo TTY teclea la conversación y el/la operador/a se la dice a la otra persona sin dispositivo TTY. Al igual, la persona sin dispositivo responde oralmente, y el/la operador/a la teclea para que aparezca en la pantaya del dispositivo TTY. El Servició de Retransmición también le puede ayudar con llamadas internacionales.

Talvez estará pensando que este tipo de servicio es costozo. Al contrario, es completamente gratituo. Todos los consumidores de servicio telefonico pagan un sobrecargo en sus facturas mensuales. Los fondos del sobrecargo pagan por este y otros servicios para personas con limitaciones.

Para más infomación, llame a:

MCI/CRS: 800-855-3000 (voz/TTY)

Sprint/CRS: 888-877-5381 (voz/TTY)

Si tiene dificultad haciendose entender por teléfono, el servicio "Voz a Voz" le puede ayudar. 800-854-7784